

Note

***In re K.I.*: An Urgent Need for a Uniform System in the Treatment of the Critically Ill Infant—Recognizing the Sanctity of Life of the Child**

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The primary concern of physicians caring for children must be the best interests of the individual child. All infants and children have intrinsic value and deserve our respect and protection. This is true whether or not they are handicapped or have the potential to be handicapped and regardless of whether this handicap is physical or mental. This means that all children, regardless of handicap either actual or potential, have a justified claim to life and therefore to such medical treatment as is necessary to either improve or prolong life.¹

AS SAD AS it is, the above quoted premise is not widely held. Instead, the general view is that medical treatment should be withheld from critically ill newborns. The focus of this Note, *In re K.I.*,² is a case involving an infant born in Missouri with several treatable ailments. It is just one of a long list of cases in which medical treatment was withheld from a child deemed unworthy of life-sustaining treatment. In fact, the case follows a troubling and checkered history of court cases and legislative attempts to deal with the problem of critically ill children. This case is of particular importance because the decision to

* Class of 2001. This Note is dedicated to the author's mother, Julia Guevara, and her sister, Perla Guevara—her pillars of strength, her role models, her everything—for their virtue, courage, love, support, and encouragement; to Maria Jimenez for her friendship and understanding; and to Debra Johnson, Melanie Slaton, Gina DeVito, and Carol Wilson for their example, graciousness, faith, and trust in her.

1. Bioethics Committee, Canadian Paediatric Society, *Treatment Decisions for Infants and Children*, at <http://www.cps.ca/english/statements/B/b86-01.htm> (reaffirmed Feb. 2000).

2. 735 A.2d 448 (D.C. 1999).

withhold treatment was made by the state, rather than the child's parents.

This Note focuses on the court's failure to adopt and follow a uniform system in ordering treatment for critically ill infants. This Note argues that the United States Supreme Court's opinion in the seminal case of *Cruzan v. Missouri Department of Health*³ is applicable to the case of the critically ill infant. In *Cruzan*, the Court recognized the sanctity of an individual's life and affirmed the proscription against the use of substituted judgment in the absence of substantial proof that the decision to forego life-sustaining treatment reflects the wishes of the patient.⁴ Although it is conceded that *Cruzan* concerned an adult woman whose parents wanted her removed from life-sustaining equipment, this Note is premised on the view that infants should be accorded the same respect. No one—not parents, hospital, or state—should negate a child's right to medical treatment, particularly when the child has a chance of survival, nor should they decide when and how the child should die.

Part I of this Note is devoted to an overview of the treatment by the United States legal system of the critically ill newborn beginning with the case of the Bloomington Baby.⁵ Part II of this Note discusses *In re K.I.*⁶ Part III analyzes the principles espoused in *In re K.I.*, including the traditional role of parents and the development of the state's role as *parens patriae* in child neglect cases. Part III also argues that the *K.I.* court departed from current practices in terminating parental rights. Finally, in Part IV, the *Cruzan* principle—which encourages respect for life—is discussed and applied to the case of the critically ill infant. In particular, Part IV suggests that the child's perspective must be considered by the medical profession when deciding whether to treat the critically ill child.

I. Background: The Fate of the Critically Ill Child Since the Death of the Bloomington Baby

It has been over seventeen years since the public first heard about the horror of withholding medical treatment from critically ill newborns. The matter came to public attention in 1982 with the death

3. 497 U.S. 261 (1990).

4. See *id.* at 280.

5. See THOMAS A. NAZARIO, IN DEFENSE OF CHILDREN 79–80 (Charles Scribner's Sons ed., 1988).

6. 735 A.2d 448 (D.C. 1999).

of a Bloomington, Indiana, infant ("Bloomington Baby").⁷ The infant male was born with Down Syndrome and an esophageal obstruction which prevented oral feeding.⁸ Although the obstruction was reversible, the Bloomington Baby's parents refused treatment rather than consent to life-preserving surgery.⁹ Alarmed by the parents' resolution, the hospital sought a court order to force treatment.¹⁰ The court, however, sided with the parents and concluded that the parents had not neglected their child under the state's child neglect statutes.¹¹ While the hospital appealed the trial court's decision,¹² all nutrients, hydration, and treatment were withheld from the Bloomington Baby for six days until he died on April 15, 1982.¹³ Since the death of the Bloomington Baby, many other children have suffered a similar fate, albeit under different legal standards and theories.

A. The Reagan Administration and Section 504:¹⁴ The Case of Baby Jane Doe

Shock over the Bloomington Baby's death caused a flurry of legislative efforts to prevent the practice of withholding medical treatment from disabled newborns. The first of these endeavors occurred on May 18, 1982, under a mandate of the Reagan administration, whereby the Director of the Department of Health and Human Services ("DHHS") issued a notice to federally funded hospitals "reminding" them that newborn infants with handicaps were protected by section 504 of the 1973 Rehabilitation Act ("section 504").¹⁵ Section 504 states, in pertinent part,

7. See NAZARIO, *supra* note 5, at 79.

8. See *id.*

9. See *id.* at 79-80.

10. See Janna C. Merrick, *Critically Ill Newborns and the Law*, 16 J. LEGAL MED. 189, 194-95 (1995).

11. See *id.* at 195 n.20.

12. See *id.* at 195. The United States Supreme Court denied the petition for certiorari. See *Infant Doe v. Bloomington Hosp.*, 464 U.S. 961 (1983).

13. See NAZARIO, *supra* note 5, at 80 (The child's parents refused to allow doctors to feed the child intravenously. "[I]nstead a note was placed by his bed which read, 'Do not feed, provide liquids, or any medical care.' It took six excruciating long days for little Infant Doe to die. For four of those six days he cried; on his last day, he simply starved to death.").

14. 29 U.S.C. § 794(a) (1994).

15. The notice warned hospitals that they would be in violation of section 504 if they disallowed such infants to remain in their care after the child's parents or guardian withheld consent to treatment. See *Bowen v. Am. Hosp. Ass'n*, 476 U.S. 610, 617 (1986).

[n]o otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.¹⁶

The reminder, soon codified as the "Interim Final Rule,"¹⁷ required hospitals to post signs in maternity and pediatric units advising persons aware of children denied food or care to contact a twenty-four hour hotline or child protective services.¹⁸ Several medical organizations successfully challenged the rule on purely procedural grounds in *American Academy of Pediatrics v. Heckler*.¹⁹ The plaintiffs alleged, and the court agreed, that the DHHS failed to provide public notice of the rule or a thirty day waiting period for its implementation.²⁰

Undeterred by the *Heckler* challenge, the DHHS redrafted the rule in 1983 and invited public comment.²¹ The "Final Rule," as it came to be known, maintained the same reporting requirements as its predecessor and required federally assisted state child protective services agencies to exercise their full authority under state law to prevent instances of medical neglect of handicapped infants.²²

While the DHHS was in the process of promulgating the Final Rule, the applicability of section 504 to cases concerning disabled infants was tested in the 1983 case of *Weber v. Stony Brook Hospital*.²³ There, Baby Jane Doe, an infant girl, was born with several disorders, including spina bifida,²⁴ hydrocephalus,²⁵ and microcephaly.²⁶ Although surgery was an option to correct several of the child's ailments, her parents opted to withhold surgery and treat their daughter with antibiotics.²⁷ The parents' decision to withhold surgery was chal-

16. 29 U.S.C. § 794(a).

17. *Bowen*, 476 U.S. at 618.

18. *See id.*

19. 561 F. Supp. 395 (D.D.C. 1983).

20. *See id.* at 400-01.

21. *See Bowen*, 476 U.S. at 619.

22. *See id.*

23. 467 N.Y.S.2d 685 (App. Div. 1983).

24. Spina bifida is a surgically correctable medical condition characterized by "a failure of closure of the bones and the coverings of the spinal cord." *Id.* at 686.

25. Hydrocephalus is a medical "condition in which fluid fails to drain from the cranial areas" and which can be relieved by surgical procedure. *Id.*

26. Microcephaly is a medical condition characterized by "a small head circumference." *Id.*

27. *See id.*

lenged in Suffolk County's Supreme Court.²⁸ A guardian ad litem for the infant was appointed to consent to the surgeries.²⁹ The *Weber* court vacated the appointment of the guardian and held that the parents' choice to withhold surgery was in the infant's best interest.³⁰ The DHHS subsequently filed charges against University Hospital³¹ for refusing to make available Baby Jane Doe's medical records for inspection.³² The court held that the hospital had not violated section 504, because it was at all times willing to perform the surgical procedures and was impeded in this pursuit only when the parents refused to consent.³³

The Final Rule was set aside by court order the following year in the case of *United States v. University Hospital*.³⁴ There, the government appealed the district court's decision that the hospital had not violated section 504 by refusing the DHHS access to Baby Jane Doe's medical records.³⁵ The court held that Congress did not intend section 504 to apply to cases in which treatment is denied to "defective" newborns, nor did it require hospitals to monitor the medical treatment of such infants.³⁶ Instead, the court reasoned that section 504 was meant only to prevent discrimination against handicapped adults and older children and protect their access to federal programs.³⁷

In 1986, the United States Supreme Court finally laid to rest the debate over the Final Rule's authority under section 504. In *Bowen v. American Hospital Ass'n*,³⁸ the Court held that section 504 did not authorize the investigative actions proposed by the DHHS and that the rule was invalid.³⁹ Moreover, the Court held that the Final Rule was not needed to prevent hospitals from denying treatment to handicapped infants as no evidence was presented by the director of the DHHS showing that hospitals discriminated against handicapped newborns.⁴⁰ Instead, the Court found that in the forty-nine Baby Doe

28. *See id.*

29. *See id.*

30. *See id.* at 687.

31. The full name of Stony Brook Hospital is University Hospital, State University of New York at Stony Brook.

32. *See United States v. Univ. Hosp.*, 575 F. Supp. 607 (E.D.N.Y. 1983).

33. *See id.* at 614.

34. 729 F.2d 144 (2d Cir. 1984).

35. *See id.* at 146.

36. *See id.* at 157-58.

37. *See id.* at 159, 161.

38. 476 U.S. 610 (1986).

39. *See id.* at 647.

40. *See id.* at 632-34.

cases cited by the DHHS, there were no instances in which a hospital refused to treat an infant after a parent consented to treatment.⁴¹ The Court reasoned, "[a] hospital's withholding of treatment when no parental consent has been given cannot violate [section] 504, for without the consent of the parents or a surrogate decision maker the infant is neither 'otherwise qualified' for treatment nor has he been denied care 'solely by reason of his handicap.'"⁴² In retrospect, the focus of the Final Rule was misplaced. It targeted hospitals rather than parents who refused to consent to the medical treatment of their children. The Final Rule did nothing to prevent the fate of future Bloomington babies.

B. The Child Abuse Prevention and Treatment Act—Congressional Reaction: The Case of Baby Lance Steinhaus

While protection of handicapped infants was being argued under section 504, Congress restructured existing anti-child abuse laws in 1984 to include the withholding of treatment from critically ill infants.⁴³ The 1984 Amendments to the Child Abuse Prevention and Treatment Act⁴⁴ ("CAPTA") characterized the failure to treat disabled infants as a form of child abuse.⁴⁵ CAPTA defined medical neglect as the "failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's (or physicians') reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions."⁴⁶ But while the new provisions purported to halt the withholding of medical treatment to infants, they were not all inclusive. Doctors and medical personnel were afforded the freedom to exercise their medical judgment to withhold treatment from infants who were chronically and irreversibly comatose; those who would not benefit from any treatment but whose lives would only be prolonged; and those who would not survive treatment, the application of which would be considered futile and inhumane.⁴⁷

In 1986, CAPTA was tested in the case of a Minnesota baby boy, Lance Steinhaus.⁴⁸ The child lapsed into what his doctors diagnosed

41. See *id.* at 634.

42. *Id.* at 630.

43. See Merrick, *supra* note 10, at 200.

44. 45 C.F.R. § 1340.15 (1998).

45. See *id.* § 1340.15(b)(1).

46. *Id.* § 1340.15(b)(2).

47. See *id.* §§ 1340.15(b)(2)(i)–(iii).

48. See Merrick, *supra* note 10, at 201.

as a persistent vegetative state ("PVS") after being beaten by his father at five weeks of age.⁴⁹ Convinced that Lance would not recover, his doctors filed a petition for a "Do Not Resuscitate Order" ("DNR") with the court. Lance's mother joined in the petition.⁵⁰ The judge denied the petition on grounds that the infant did not meet the CAPTA exception for patients who are chronically and irreversibly comatose, as he was diagnosed only as PVS by his physicians.⁵¹ A month later, Lance's doctors and mother filed a motion to amend the order to change Lance's condition from PVS to chronically and irreversibly comatose, and to state that the withholding of treatment would not constitute medical neglect.⁵² The court subsequently amended the order to show that the child met the CAPTA exception and instructed that medical attention be withheld.⁵³ Baby Lance Steinhaus died in February 1987.⁵⁴

C. Emergency Medical Treatment and Active Labor Act: The Case of Baby K

In 1992, a Virginia court held that CAPTA may be raised only by the appropriate child protective services agency and denied its application in a case involving a hospital which sought a court order to discontinue the treatment of a baby girl born with anencephaly.⁵⁵ Born on October 13, 1992, Baby K was kept on mechanical ventilation at the request of her mother due to respiratory distress.⁵⁶ The hospital urged Baby K's mother to permit a DNR in order to terminate ventilator treatment as no therapeutic or mitigating purpose was served by continued treatment.⁵⁷ When Baby K's mother objected to the doctors' request, they transferred the child to a nursing home on the condition that the baby be readmitted to the hospital for respiratory difficulties.⁵⁸ By April 1993, Baby K was treated for respiratory distress twice.⁵⁹ The hospital sought declaratory and injunctive relief under

49. *See id.*

50. *See id.*

51. *See id.*

52. *See id.*

53. *See id.*

54. *See id.* at 202.

55. *See In re Baby K*, 832 F. Supp. 1022, 1029 (E.D. Va. 1993). Anencephaly is a "congenital malformation in which a major portion of the brain, skull, and scalp are missing." *In re Baby K*, 16 F.3d 590, 592 (4th Cir. 1994).

56. *See In re Baby K*, 832 F. Supp. at 1025.

57. *See id.*

58. *See id.*

59. *See id.*

four federal statutes, including section 504,⁶⁰ CAPTA, the Americans with Disabilities Act⁶¹ ("ADA"), and the Emergency Medical Treatment and Active Labor Act⁶² ("EMTALA"), to allow it to discontinue "futile treatment" of the infant.⁶³

The EMTALA requires that hospitals provide stabilizing medical treatment to any person who comes to an emergency department in an emergency medical condition when treatment is requested on the person's behalf.⁶⁴ The court held that, under EMTALA, the use of a mechanical ventilator is not futile or inhumane in relieving the symptoms of respiratory difficulty.⁶⁵

On appeal, the court upheld the trial court's decision.⁶⁶ The appellate court maintained that the hospital had a duty to provide treatment to prevent material deterioration of the patient.⁶⁷ In the case of Baby K, therefore, the hospital's duty was to prevent deterioration of the baby's respiratory condition without regard to her anencephalic condition.⁶⁸ "Uniform treatment of emergency medical conditions[.]" the court concluded, "... require[d] the [h]ospital to provide Baby K with the same treatment that [it] provides all other patients experiencing [respiratory distress]."⁶⁹ A tracheotomy and implantation of an endotracheal tube were eventually performed on Baby K and, as of

60. See *id.* at 1027. The court held that the hospital's wish to withhold ventilator treatment from Baby K over the mother's objection would violate section 504 because the child was "otherwise qualified" under the Act. See *id.* at 1028.

61. 42 U.S.C. § 12132 (1994). The ADA provides, "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." *Id.* The court held that the ADA:

does not permit the denial of ventilator services that would keep alive an anencephalic baby when those life-saving services would otherwise be provided to a baby without disabilities at the parent's request. The Hospital's reasoning would lead to the denial of medical services to anencephalic babies as a class of disabled individuals. Such discrimination against a vulnerable population class is exactly what the American with Disabilities Act was enacted to prohibit.

In re Baby K, 832 F. Supp. at 1029.

62. 42 U.S.C. § 1395dd(b) (1994).

63. See *In re Baby K*, 832 F. Supp. at 1027.

64. See 42 U.S.C. § 1395dd(a).

65. See *In re Baby K*, 832 F. Supp. at 1027.

66. See *In re Baby K*, 16 F.3d 590, 598 (4th Cir. 1994).

67. See *id.* at 595.

68. See *id.*

69. *Id.* at 596.

the date of the final ruling, she had not returned to the hospital for breathing assistance.⁷⁰

D. Child Neglect: The Case of Baby Terry

After the unprecedented case of Baby K, it seemed as if the courts were finally defending the rights of disabled infants regardless of parental consent or objections from the medical profession. But in the year following the resolution of Baby K's case, another infant was born who did not fare well under any of the laws providing life-sustaining guarantees. Baby Terry was born prematurely at twenty-three weeks gestation on May 27, 1993, in Michigan.⁷¹ He was immediately placed on a respirator due to respiratory distress. Baby Terry was also afflicted with several physical infirmities, including insufficient oxygen supply to the brain, bleeding on the brain, and bacterial and fungal infections.⁷² Prior to his birth, Baby Terry's doctors had erroneously predicted that the infant would be born brain dead, and at birth they estimated he would not live more than a day.⁷³ Weeks after his birth, doctors, still convinced of Baby Terry's uncertain future, recommended that life-sustaining ventilator treatment be suspended.⁷⁴ The treatment, however, aided Baby Terry in fighting off a bacterial infection and allowed him to breathe.⁷⁵

On June 27, 1993, the Department of Social Services intervened and petitioned the court for a finding of child neglect, because Baby Terry's parents chose to continue life-sustaining treatment for their infant.⁷⁶ At the hearing on the petition, the court questioned the competency of Baby Terry's parents to make reasonable medical decisions simply because the infant's mother, Rosetta Christle, asked to obtain a second medical opinion as well as permission to seek the assistance of other medical providers.⁷⁷ Two days later, without considering expert testimony or psychological testing of the parents, the court appointed the baby's aunt as his guardian.⁷⁸ The court held that Baby Terry's

70. See James Bopp, Jr. & Richard E. Coleson, *Child Abuse By Whom?—Parental Rights and Judicial Competency Determinations: The Baby K and Baby Terry Cases*, 20 OHIO N.U. L. REV. 821, 823 (1994).

71. See *id.* at 825.

72. See *id.*

73. See *id.*

74. See *id.*

75. See *id.*

76. See *id.*

77. See *id.* at 826.

78. See *id.* at 832.

parents were emotionally unable to understand their child's condition and were, therefore, incompetent to make decisions for him.⁷⁹

Baby Terry's parents appealed. In her appellate brief, Ms. Christle implored the court that she was confident her child would live based on her prior experience with her older child.⁸⁰ Baby Terry's brother, she explained, was born five and a half months premature, weighed less at birth than Baby Terry, and had more medical problems than Baby Terry.⁸¹ Despite these difficulties, Baby Terry's brother experienced no medical problems as he got older and was an "A" student.⁸² Ms. Christle also testified that she was prepared to accept the responsibility of caring for Baby Terry in the event he suffered physical and/or mental disabilities.⁸³ Ms. Christle's arguments were futile, and on appeal, the Genesee Circuit Court affirmed the probate court's decision.⁸⁴ By this time, Baby Terry had successfully survived three months of life. Following the court's order, Baby Terry's oxygen supply was reduced from one hundred percent to twenty percent and, shortly thereafter, he died in his mother's arms.⁸⁵

Ms. Christle requested leave to appeal on grounds that this type of case was capable of repetition.⁸⁶ On December 27, 1995, Ms. Christle's petition was denied.⁸⁷

E. Current Attitudes Regarding Treatment of the Critically Ill Child

As the cases above demonstrate, the practice of withholding medical treatment from critically ill newborns is widespread. The overwhelming number of cases show that the treating physician is often a leading proponent of the practice. In order to understand the reasons why the practice of withholding medical care is so widespread and to gauge the future of the critically ill child, it is helpful to examine the medical profession's attitude concerning treatment of the critically ill child.

To date, no nationwide studies have been conducted to determine current hospital policies regarding the treatment of disabled

79. *See id.*

80. *See id.*

81. *See id.*

82. *See id.*

83. *See id.* at 833.

84. *See id.* at 826-27.

85. *See id.* at 827.

86. *See id.*; *see also In re Terry Achtabowski*, 548 N.W.2d 628 (Mich. 1995).

87. *See* 548 N.W.2d 628 (Mich. 1995).

newborns. However, in 1991, the Journal of the American Medical Association ("JAMA") published a revealing study regarding the attitudes, and possibly the practice, of medical personnel regarding life-sustaining treatment for disabled newborns.⁸⁸ Two hundred and forty-seven professionals, consisting of neonatologists, neonatal fellows, pediatric residents, neonatal nurses, and infant care review committee members of six New York city hospitals—all leaders in the care of women and children infected with the HIV virus—were surveyed.⁸⁹ The respondents were asked questions regarding the level of treatment they would recommend in several hypotheticals involving infants with varying degrees of ailments.⁹⁰

For the full-term infant with duodenal atresia (esophageal obstruction) and no other concurrent condition, all of the respondents said they would recommend intravenous feedings; of these, 99.6% said they would recommend intestinal surgery.⁹¹ For the full-term infant with a ventriculoseptal defect (congenital heart defect) and no concurrent condition, 97% responded that they would recommend open heart surgery.⁹² For the full-term infant with severe chronic kidney damage and no other concurrent condition, 89% would recommend dialysis, and 90% would recommend cardiac resuscitation if, after suffering kidney damage, the infant suffered a cardiac arrest.⁹³

The number of medical professionals who would recommend life-sustaining treatment diminished for infants born with concomitant conditions. For infants afflicted with a ventriculoseptal defect, 84% of the respondents would recommend open heart surgery for the infant with Down Syndrome or cystic fibrosis; 31% for the infant born with Tay-Sachs disease; and only 9% for the infant born with trisomy 13 syndrome.⁹⁴

The number of respondents who would withhold treatment for HIV-infected newborns is even more disheartening. Ninety-five percent would recommend intravenous feeding and only 75% intestinal

88. See Betty Wolder Levin et al., *Treatment Choice for Infants in the Neonatal Intensive Care Unit at Risk for AIDS*, 265 JAMA 2976 (1991).

89. See *id.* at 2976.

90. See *id.* at 2977.

91. See *id.* at 2978.

92. See *id.*

93. See *id.*

94. See *id.* Cystic fibrosis is a hereditary disease of the exocrine glands characterized by breathing difficulties, infection, and fibrosis. See RANDOM HOUSE WEBSTER'S DICTIONARY 174 (3d ed. 1998). Trisomy 13 syndrome is a chromosomal abnormality with severe neurologic impairment which almost always leads to death within the first two years of life. See Levin et al., *supra* note 88, at 2979.

surgery for the child afflicted with duodenal atresia.⁹⁵ Less than half of the respondents, 42%, would recommend open heart surgery for a child with ventriculoseptal defect.⁹⁶ And fewer still, only 29%, would recommend either kidney dialysis for the child with chronic kidney failure, or cardiac resuscitation for the child with chronic kidney failure and cardiac arrest.⁹⁷ Many of the respondents said that if they were certain the child was HIV-infected, they would withhold aggressive medical treatments, just as they would in the case of an infant afflicted with Tay-Sachs disease.⁹⁸ Others reported they would withhold some treatment from infants born to mothers infected with HIV, despite uncertainty of the child's infection with the virus.⁹⁹ The latter group based its decision on the belief that children born to women with AIDS would have poor quality of life due to the certain death of the mother and poor social environment.¹⁰⁰ The JAMA study suggests that medical personnel are often guided by quality of life judgments in the treatment of the critically ill child. The more physically afflicted a child is, the less likely medical providers are to come to the child's aid.

In June 1999, JAMA published a study regarding the differences in attitudes among medical professionals, children with no disabilities, disabled children, and their parents over the quality of life and the treatment of the critically ill child ("Saigal study").¹⁰¹ The study's subjects were asked to rate five hypothetical health states.¹⁰² Neonatologists and nurses had similar preferences for the five health states.¹⁰³ Fifty-nine percent of the physicians and sixty-eight percent of the nurses rated one or more of the health states as worse than death.¹⁰⁴

95. See Levin et al., *supra* note 88, at 2978.

96. See *id.*

97. See *id.*

98. See *id.* at 2980.

99. See *id.*

100. See *id.*

101. See Saroj Saigal et al., *Differences in Preferences for Neonatal Outcomes Among Health Care Professionals, Parents, and Adolescents*, 281 JAMA 1991-97 (1999). A total of 742 individuals were interviewed in a two-year period, including 100 neonatologists from hospitals throughout Canada; 103 neonatal nurses from three regional neonatal intensive care units; 264 adolescents, aged twelve through sixteen years, 140 of whom were extremely low birth weight infants; and 275 parents of the adolescents interviewed. See *id.* at 1991.

102. See *id.* at 1993. The five states were represented by children with varying degrees of physical, emotional, and learning disabilities. See *id.*

103. See *id.* at 1991.

104. See *id.* The health states rated as worse than death included those represented by children whose abilities to see, hear, and speak were partially or completely impaired. These children also needed special equipment or assistance to eat, bathe, dress, and use the toilet. See *id.*

The health professionals rated the two most severely disabled health states “significantly lower than [the] parents.”¹⁰⁵ Fifty percent of the responding adolescents rated at least one of the health states as worse than death, a number that was “significantly fewer than the health professionals.”¹⁰⁶ The authors of the study concluded that “[w]hen asked to rate the health-related quality of life for the hypothetical conditions of children, health care professionals tend to provide lower utility scores than do adolescents and their parents.”¹⁰⁷

The Saigal study cited two other studies performed on adult subjects concerning adult patients in which the results were in accord with their study regarding patient attitudes about the quality of life.¹⁰⁸ In the first study, concerning end-stage renal disease, patients were found to value their own health conditions more highly than health professionals.¹⁰⁹ The second study concerned patients with cancer.¹¹⁰ There, researchers found that cancer patients were willing to choose radical treatment with minimal chance of benefit. Subjects without cancer, including health professionals, would forego radical treatment.¹¹¹

As the above studies indicate, many health professionals do not value the life of patients to the same degree as patients or the parents of critically ill children. These attitudes, as the Saigal study suggests, affect decisions regarding the administration of life-saving procedures to critically ill children.¹¹² According to both studies, the future of the critically ill child is dismal at best.

II. The Case: *In re K.I.*

Recently, the District of Columbia Court of Appeals decided that the state, as *parens patriae*,¹¹³ could order a DNR in the child's best

105. *Id.* at 1994.

106. *Id.* at 1995.

107. *Id.* at 1991.

108. *See id.* at 1996.

109. *See id.* (citing D.N. Churchill et al., *Measurement of quality of life in end-stage renal disease: the time trade-off approach*, 10 CLINICAL INVEST. MED. 10, 14–20 (1987)).

110. *See id.* (citing M.L. Slevin et al., *Attitudes to chemotherapy: comparing views of patients with cancer with those of doctors, nurses, and general public*, 300 BRIT. MED. J. 1458–60 (1990)).

111. *See id.*

112. *See* NAZARIO, *supra* note 5, at 81 (“[D]octors may place their own feelings and priorities above the legal rights of the child or the parents.”).

113. The term *parens patriae* refers to “[t]he state regarded as a sovereign; the state in its capacity as provider of protection to those unable to care for themselves.” BLACK’S LAW DICTIONARY 1137 (7th ed. 1999).

interest.¹¹⁴ The case involved an infant girl born prematurely at twenty-six weeks gestation, who developed broncho pulmonary dysplasia,¹¹⁵ and was afflicted with reactive airways disease,¹¹⁶ gastro-esophageal reflux, and hemoglobin SC disease (a mild variant of sickle cell disease).¹¹⁷ The child required a heart monitor, lung medication, and continuous oxygen.¹¹⁸ Five weeks after baby K.I.'s release from the hospital, the DHHS instigated child neglect proceedings against the mother, B.I., after they were prompted by a call from K.I.'s putative father¹¹⁹ to the hospital. K.I. was removed from her mother's custody and placed in a hospital.¹²⁰ On July 21, 1998, nearly seven months after K.I. was taken from her mother, K.I. was transferred to another hospital where, on the same day, she experienced cardiac arrest and hypoxia, a deprivation of oxygen to the cells and to the brain.¹²¹ The following day she suffered a seven hour seizure which was controlled with Phenobarbital medication.¹²² The medication caused K.I. to lapse into a "pentobarblike coma."¹²³ On August 22, 1998, K.I. was returned to the hospital, where she continued to experience medical problems.¹²⁴

On August 26, 1998, the hearing on the neglect petition was held. The petition alleged that B.I. would sometimes remove the oxygen and monitor from the child and failed to give her lung medication.¹²⁵ The neglect petition also alleged that K.I.'s mother failed to schedule the child for medical appointments. In court, a DHHS employee testified that B.I. smelled of alcohol, was incoherent, and could not walk straight when he initially contacted her.¹²⁶ The trial court found K.I. was a neglected child based solely on the testimony of the DHHS em-

114. See *In re K.I.*, 735 A.2d 448, 467 (D.C. 1999).

115. Broncho pulmonary dysplasia is "an abnormal condition of the lung cells which requires a child to use oxygen." *Id.* at 451.

116. Reactive airways disease is a lung condition "characterized by wheezing." *Id.*

117. Sickle cell disease is "a chronic hereditary anemia . . . in which oxygen-deficient blood cells assume a crescent shape." RANDOM HOUSE WEBSTER'S DICTIONARY 666 (3d ed. 1998).

118. See *In re K.I.*, 735 A.2d at 451.

119. "D.M." did not submit to a paternity test, but nonetheless claimed that he was K.I.'s father. See *id.* at 451 n.1.

120. See *id.* at 451.

121. See *id.* at 451-52.

122. See *id.* at 452.

123. *Id.*

124. See *id.*

125. See *id.*

126. See *id.* In addition, K.I.'s father testified that B.I. consumed three beers on a daily basis and became intoxicated. See *id.*

ployee and the child's father.¹²⁷ K.I.'s mother did not attend the hearing in which the court determined that, although she had liberty interests in the child, she had placed the child at risk through her drinking and failure to provide care.¹²⁸

Because of K.I.'s continued medical problems, the trial court held a hearing to determine whether aggressive resuscitation efforts should be employed in the event K.I. suffered pulmonary or respiratory arrest.¹²⁹ The child's medical guardian ad litem requested a DNR order.¹³⁰ The guardian called six expert witnesses, only one of whom was K.I.'s treating physician.¹³¹ Expert testimony revealed that K.I. was not dependent on significant life support measures; she was able to breathe on her own and her heart beat independently.¹³² Yet, one expert described K.I. as neurologically devastated and, while capable of feeling pain and discomfort, was incapable of reacting to her environment, understanding the events around her, and giving or receiving love.¹³³ All of the expert witnesses recommended that no aggressive efforts at resuscitation be taken.¹³⁴

The trial court issued a DNR order which provided that "[i]n the event of cardiac and/or pulmonary arrest, the following procedures for resuscitation shall represent the *exclusive* methods of intervention to be performed on [K.I.]: (1) Blow by Oxygen[;] (2) Bag-Mask Ventilation[; and] (3) Intra-muscular & Sub-cutaneous Medications."¹³⁵ K.I.'s mother appealed the trial court's decision, contending that she, as the parent, had the right to decide whether K.I. should be resuscitated.¹³⁶ K.I.'s mother also argued that the court erred in applying the best interests of the child standard rather than the substituted judgment standard in issuing the DNR. She also argued that the court erred in employing the preponderance of the evidence standard in the neglect proceedings rather than the clear and convincing evi-

127. See *id.* at 451 n.2.

128. See *id.*

129. See *id.* at 458.

130. See *id.* at 457.

131. See *id.* at 458. The other experts included Dr. Gabriel Jacob Hauser, a Georgetown University bioethics professor; Dr. Noreen Crain, a fellow in the Critical Care Unit at Children's Hospital; Reverend Jeanne Brienneis, a bioethics expert; and Dr. Tomas Jose Silber, a physician and chairman of the hospital's office of ethics. See *id.* at 458-59.

132. See *id.* at 458.

133. See *id.*

134. See *id.* at 458-59.

135. *Id.* at 450.

136. See *id.*

dence standard.¹³⁷ K.I.'s father supported the DNR order, but complained that the trial court should have recognized his right to parental privacy and parental autonomy.¹³⁸

On appeal, the court agreed that the trial court had the authority, as *parens patriae*, to rule in the best interests of the child.¹³⁹ The trial court had held:

[T]he issuance of [a] DNR order must be predicated upon a finding by clear and convincing evidence *both* that it is in [K.I.'s] best interests to forego aggressive revival measures, and that [B.I.'s] refusal to consent to the issuance of the DNR order is unreasonably contrary to [K.I.'s] well-being.¹⁴⁰

The appellate court held that "in exercising its role as *parens patriae* . . . the trial court, carefully and thoughtfully, determined by clear and convincing evidence that it was in K.I.'s best interest to avoid use of aggressive resuscitation efforts which cause pain and discomfort."¹⁴¹ Based on this finding, the court upheld the DNR order.¹⁴²

III. The *K.I.* Court Failed to Adhere to Current Principles and State Law in Terminating a Parent's Rights to Her Child

A. The Rights of Parents to Make Medical Decisions on Behalf of a Child Is Limited by the States' Interest in Protecting Children

The parents' role in making medical decisions for a child is based upon the "special relationship that parents have with their children [giving] rise to reciprocal rights and obligations."¹⁴³ According to one scholar, a parent's right over his child is protected by the United States Constitution, which affords parents the right to "establish a home and bring up children."¹⁴⁴ "This right is not because of 'absolute authority over family members, but rather because society be-

137. See *id.*; see also discussion *infra* Part III.B.

138. See *In re K.I.*, 735 A.2d at 450.

139. See *id.*

140. *Id.* at 456.

141. *Id.*

142. See *id.*

143. James Bopp, Jr., *Protection of Disabled Newborns: Are There Constitutional Limitations?*, 1 ISSUES L. & MED. 173, 177 (1985).

144. *Id.* at 180 (quoting *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923)).

lieves that parental authority usually will be exercised to advance the children's welfare.'"¹⁴⁵

However, a parent's right over a child is not absolute. "Parental rights are limited by the interests of the child and the responsibilities of the state [P]arents do not have the right to act contrary to the child's welfare."¹⁴⁶ In fact, the Constitution does not protect a parent who either abuses or neglects a child.¹⁴⁷ Included in the definition of abuse or neglect are decisions by parents to withhold treatment from handicapped newborns.¹⁴⁸ It is in this situation that states take an active role in protecting children on grounds that the preservation of life is one of the most compelling state interests.¹⁴⁹ "The state has a compelling interest in insuring that all of its citizens' Fourteenth Amendment's [sic] right to life is protected."¹⁵⁰ Thus, when a child's right to life is threatened by abusive or neglectful parents, the state, as *parens patriae*, may intervene to protect the child.¹⁵¹

B. As *Parens Patriae*, the State Has Authority to Act in the Child's Best Interest

The term *parens patriae* literally means "parent of his country" and refers to the traditional role of the state as the sovereign and guardian of its minor citizens.¹⁵² Today the power is vested in each state and is particularly relevant in guardianship law.¹⁵³ *Parens patriae* is the state's authority to limit parental freedom and authority in matters affecting a child's welfare.¹⁵⁴ Under the state's supervision, appointed guardians act in the best interests of the child.¹⁵⁵

145. *Id.* (quoting *Halderman v. Pennhurst State Sch. & Hosp.*, 707 F.2d 702, 712 (3d Cir. 1983) (Rosenn, J., concurring)).

146. *Id.* at 181.

147. *See id.* at 183.

148. *See id.*

149. *See id.*

150. *Id.*

151. *See id.* at 181.

152. BLACK'S LAW DICTIONARY 1137 (7th ed. 1999). The doctrine of *parens patriae* regards the state as "the ultimate parent of every child." JOSEPH M. HAWES, *THE CHILDREN'S RIGHTS MOVEMENT: A HISTORY OF ADVOCACY AND PROTECTION* 2 (1991) ("When the morals, or safety, or interests of the children require it, the courts could intervene and withdraw the infants from the custody of the father or mother and place the care and custody of them elsewhere.") (citations omitted).

153. *See* Daniel B. Griffith, *The Best Interests Standard: A Comparison of the State's Parens Patriae Authority and Judicial Oversight in Best Interests Determinations for Children and Incompetent Patients*, 7 ISSUES L. & MED. 283, 288 (1991).

154. *See* *Prince v. Massachusetts*, 321 U.S. 158, 167 (1944).

155. *See* Griffith, *supra* note 153, at 288.

Instead of seeking to abrogate a parent's rights completely, "[u]nder the *parens patriae* doctrine, the state seeks to protect family autonomy and the parents' right to the companionship, care, custody, and management of their children."¹⁵⁶

The fundamental liberty interest of natural parents . . . does not evaporate simply because they have not been model parents or have lost temporary custody of their child to the State. Even when blood relationships are strained, parents retain a vital interest in preventing the irretrievable destruction of their family life.¹⁵⁷

Thus, courts must provide parents with fair procedural protections.¹⁵⁸ The state must also support its allegations of parental incompetence by at least clear and convincing evidence.¹⁵⁹

The best interests of the child standard is the leading standard used by courts to terminate a parent's rights to the care and custody of a child upon clear and convincing evidence of abuse or neglect.¹⁶⁰ In its inception, the standard treated the child as an object to be owned, but today the standard is a flexible one making the needs of the child its focus.¹⁶¹ However, no uniform standard exists which states may apply in every given situation.¹⁶² This lack of uniformity engenders a standard which is "indeterminative and speculative, vague, broad and elusive, subject to a judge's subjective value judgments, and conducive to overgeneralization instead of meticulous fact-finding."¹⁶³ In essence, the courts are afforded ample discretion in determining what is in the child's best interest.¹⁶⁴ Even in those states which provide factors to be considered in determining the child's best interests, the courts alone decide the weight to give each factor.¹⁶⁵

In the medical setting, "the best interests of the child will favour the provision of life-sustaining treatment."¹⁶⁶ In those circumstances in which the best interests of the child may be uncertain, "[t]he pre-

156. *Id.* at 289.

157. *Santosky v. Kramer*, 455 U.S. 745, 753 (1982).

158. *See id.* at 753-54.

159. *See id.* at 769.

160. *See Griffith*, *supra* note 153, at 283. The best interest of the child has been defined "as the balance of potential benefit over potential harm or distress resulting from the pursuit of a given line of treatment." Bioethics Committee, Canadian Paediatric Society, *supra* note 1.

161. *See Griffith*, *supra* note 153, at 292.

162. *See id.* at 295.

163. *Id.* (citations omitted).

164. *See id.*

165. *See id.* at 299-300.

166. Bioethics Committee, Canadian Paediatric Society, *supra* note 1.

supposition . . . should be in favour of life-saving or sustaining treatment.”¹⁶⁷

Nevertheless, restraints have been placed on a state’s *parens patriae* power to interfere in the family relationship.¹⁶⁸ This check on the state’s power is consistent with the premise that a child’s interest is best served when the child is placed in the custody of his parents.¹⁶⁹ The current trend is to preserve the family unit and employ rehabilitative efforts to solve family problems, instead of merely protecting the child from abuse and neglect.¹⁷⁰ The “termination of parental rights determinations become [sic] necessary only when rehabilitative efforts have broken down [T]ermination of parental rights proceedings generally represent [sic] the final stage of state intervention.”¹⁷¹

As mentioned above, the court in *K.I.* determined it was in the child’s best interests to terminate K.I.’s mother’s parental rights and affirm an order not to resuscitate the child in the event of heart or respiratory failure.¹⁷² The court found “by clear and convincing evidence”¹⁷³ that the child had been neglected pursuant to District of Columbia Code sections 16-2301(9)(B), (C), and (F).¹⁷⁴

District of Columbia Code section 16-2320(a),¹⁷⁵ from which the court derived its power to terminate B.I.’s parental rights,¹⁷⁶ provides for the rehabilitation of the parent found to be in violation of section 16-2301. Section 16-2320 provides in part:

If a child is found to be neglected, the Division exercising juvenile jurisdiction shall also have jurisdiction over any natural person who is a parent or caretaker of the child to secure the parent or caretaker’s full cooperation and assistance in the entire rehabilitative process and may order any of the following dispositions which will

167. *Id.*

168. *See* Griffith *supra* note 153, at 299.

169. *See id.*

170. *See id.*

171. *Id.*

172. *See In re K.I.*, 735 A.2d 448, 450 (D.C. 1999).

173. *Id.* at 452.

174. *See id.* at 451 n.2. The Code states that a neglected child is one:

(B) who is without proper parental care or control . . . necessary for his or her physical, mental, or emotional health, and the deprivation is not due to the lack of financial means of his or her parent . . . ; (C) whose parent . . . is unable to discharge his or her responsibilities to and for the child because of incarceration, hospitalization, or other physical or mental incapacity; or . . . (F) who has received negligent treatment or maltreatment from his or her parent

D.C. CODE ANN. §§ 16-2301(9)(B), (C), (F) (Supp. 2001).

175. D.C. CODE ANN. § 16-2320(a) (Supp. 2001).

176. *See* 735 A.2d at 453–54.

be in the best interest of the child: (1) [p]ermit the child to remain with his or her parent . . . subject to such conditions and limitations as the Division may prescribe, including . . . the following services for the child and his or her parent . . . (A) medical, psychiatric, or other treatment at an appropriate facility under protective supervision; (B) parenting classes; and (C) family counseling.¹⁷⁷

Contrary to the principle of fair procedural protections prior to the termination of parental rights, B.I.'s rights in the instant action were terminated at a hearing which she did not attend.¹⁷⁸ According to the "fair procedural" scheme noted above, the court had a duty to allow B.I. the right to be heard. Similarly, the court should not have based its decision on the testimony of a social services employee who knew B.I. for less than a day and the testimony of a man who had not been proven to be K.I.'s biological father. The court employed no efforts to rehabilitate the mother, whom the court found suffered from a drinking problem.¹⁷⁹ According to current *parens patriae* principles and the law of the state in which the case was decided, it was the court's duty to attempt to rehabilitate the mother in an effort to preserve the family. Instead, the *K.I.* court immediately instigated a procedure which should only be used as a means of last resort. The court summarily and irretrievably terminated B.I.'s rights to her child.

IV. A New Perspective in Making Decisions Regarding the Critically Ill Newborn

As the cases in Part I of this Note demonstrate, the courts have been inconsistent in ordering or withholding medical treatment from critically ill infants. The courts have ordered the withdrawal of life-saving procedures from infants whose ailments were treatable and not life threatening, as in the cases of the Bloomington Baby and Baby Terry. The courts have also ordered life prolonging treatment in the cases of infants who have no chance of survival, as in the case of Baby Jane Doe. Much of the inconsistency is due to the assortment of laws available to the courts, the application of which can lead to a variety of outcomes. Some of the inconsistency is due in part to the subjective views of parents, judges, and medical personnel.¹⁸⁰ In an effort to

177. D.C. CODE ANN. §§ 16-2320(a)(1)(A)-(C).

178. See *In re K.I.*, 735 A.2d at 451 n.2.

179. See *id.* The court had determined K.I. was a neglected child in part because her mother "frequently consumed alcohol." *Id.* at 454.

180. See NAZARIO, *supra* note 5, at 80.

Unfortunately, too, is the fact that all too often, many of the decisions made by parents and doctors in these circumstances turn out later to have been less than

curb the arbitrariness of decisions involving critically ill infants, a uniform rule whereby decisions are based primarily on the sanctity of the life of the child must be adopted. Such a rule would be similar to that applied to the incompetent adult in the case of *Cruzan v. Missouri Department of Health*.¹⁸¹

In *Cruzan*, Nancy Cruzan was left in a persistent vegetative state due to injuries sustained in an automobile accident.¹⁸² Ms. Cruzan's parents, as co-guardians, sought a court order for the withdrawal of nutrition and hydration when it became apparent that Ms. Cruzan would not recover her cognitive faculties.¹⁸³ The Missouri Supreme Court reversed the lower court's grant of the order, noting that the "state's interest is not in quality of life [but] in life [itself]; that interest is unqualified."¹⁸⁴ The United States Supreme Court affirmed on grounds that the testimony of Ms. Cruzan's roommate at trial did not amount to clear and convincing evidence of Ms. Cruzan's wishes to have hydration and nutrition withdrawn.¹⁸⁵ An incompetent person, the Court emphasized, "is not able to make an informed and voluntary choice to exercise a hypothetical right to refuse treatment or any other right."¹⁸⁶ The Court reasoned,

[A] State has more particular interests at stake. The choice between life and death is a deeply personal decision of obvious and overwhelming finality [A] State may properly decline to make judgments about the "quality" of life that a particular individual may enjoy, and simply assert an unqualified interest in the preservation of human life to be weighed against the constitutionally protected interests of the individual.¹⁸⁷

The Court continued,

[a]n erroneous decision not to terminate results in a maintenance of the status quo; the possibility of subsequent developments such

for the good of the child. This may be because often parents find themselves feeling guilty, grief-ridden, or even embarrassed about the child. They may have conflicting interests in maintaining previous life plans and avoiding the psychic and financial costs associated with the care of a handicapped child or may make decisions in haste or without full knowledge or disclosure about the extent of the child's defects and future.

Id.

181. 497 U.S. 261 (1990).

182. *See id.* at 266.

183. *See id.* at 265.

184. *Cruzan v. Harmon*, 760 S.W.2d 408, 420 (Mo. 1988).

185. *See Cruzan*, 497 U.S. at 285. Ms. Cruzan allegedly had a "serious conversation with a housemate friend that if sick or injured she would not wish to continue her life unless she could live at least halfway normally." *Id.* at 268.

186. *Id.* at 280.

187. *Id.* at 281-82.

as advancements in medical science, . . . changes in the law, or simply the unexpected death of the patient despite the administration of life-sustaining treatment at least create the potential that a wrong decision will eventually be corrected or its impact mitigated. An erroneous decision to withdraw life-sustaining treatment, however, is not susceptible of correction.¹⁸⁸

In so stating, the Court decided that life, rather than quality of life, was worth preserving absent clear and convincing evidence of the patient's wish to die.

In its analysis, the *Cruzan* Court cited *In re Storar*,¹⁸⁹ a case involving a "profoundly retarded" fifty-two year old man who "was always totally incapable of understanding or making a reasoned decision about medical treatment."¹⁹⁰ The man's mother refused to consent to continued blood transfusions necessary to treat her son's terminal bladder cancer.¹⁹¹ In terminating the mother's parental rights, the court found the denial of the mother's petition appropriate because "courts may not permit a parent to deny a child all treatment for a condition which threatens his life."¹⁹² The court held that because the patient was "[m]entally . . . an infant[,] . . . that is the only realistic way to assess his rights"¹⁹³ As *parens patriae*, the court intervened to protect the health and welfare of the "child." With *Storar*, the court effectively demonstrated that withholding treatment cases involving infants and incompetent adults are essentially the same under a *parens patriae* analysis.

There is a danger that the trend in inconsistent court decisions regarding the disabled infant may continue. This is evidenced by the studies of the American Medical Association¹⁹⁴ and the Saigal research team,¹⁹⁵ as well as the recent decision of *In re K.I.*¹⁹⁶ To abate this trend, the same respect accorded to incompetent adults in the throes of disabling physical conditions must be extended to the disabled child. The application of this right is not difficult in the case of the disabled infant. As the *Storar* court held, the incompetent adult—who is similar to an infant—must have his right to medical treatment preserved. Thus, the sanctity of life rather than quality of life is to be

188. *Id.* at 283.

189. 420 N.E.2d 64 (N.Y. 1981).

190. *Id.* at 72.

191. *See id.* at 69.

192. *Id.* at 73.

193. *Id.*

194. *See generally* Levin et al., *supra* note 88.

195. *See generally* Saigal et al., *supra* note 101.

196. 735 A.2d 448 (D.C. 1999).

preserved above all in the case of the critically ill infant with treatable ailments.

Perhaps most indicative of a critically ill child's right to medical treatment is the study conducted by the Saigal team.¹⁹⁷ The subjects of that study, some of whom were themselves born at extremely low birth weights, considered the lives of critically ill children valuable and deserving of medical treatment. The Saigal study was representative of the patient's perspective, which should be "incorporated when determining the preferred course of action."¹⁹⁸ This, the authors concluded, "embodies the optimal patient-physician interaction."¹⁹⁹

As the Court in *Cruzan* maintained, the decision to withdraw medical treatment and the resulting death is a recourse from which there is no turning back. Keeping the child alive, on the other hand, allows for the possibility of effective treatment and scientific breakthroughs. Moreover, the unqualified right to life subverts any possibility of subjective judgments based on ideals of the quality of life.

At birth, a child has met the constitutional requirement for personhood with full rights including a right to life. To leave the fate of a handicapped newborn to the interested discretion of parents and doctors is a complete and arbitrary denial of due process and equal protection . . . [I]t is not the court's function to heed the "stringent cry in America to terminate the lives of other people—deemed physically or mentally defective." It is the court's function to secure for each person an opportunity for life.²⁰⁰

Conclusion

In 1982, the American public denounced with horror the decision of the Indiana couple who decided to starve their child to death instead of subjecting him to life-saving treatment.²⁰¹ Since then, hospitals and the states have made the decision to withhold treatment from the critically ill newborn, despite the parents' plea to keep the child alive. One positive note, however, is the finding of the 1991 JAMA study²⁰² that medical personnel today are less inclined to let a child die who is afflicted with the same medical maladies as the Bloomington Baby. But as the same study indicates, many more would recommend withholding treatment from infants afflicted with more severe

197. See generally Saigal et al., *supra* note 101.

198. *Id.* at 1996.

199. *Id.*

200. Bopp, *supra* note 143, at 186.

201. See, e.g., Lisa Blumberg, *The Natural Destiny of the Bloomington Baby*, Ragged Edge Online, at <http://www.ragged-edge-mag.com/0700/0700ful.htm> (July/Aug. 2000).

202. See Levin et al., *supra* note 88.

health problems, including children who may be infected with the HIV virus. As demonstrated by the case of *In re K.I.*, the courts also continue to allow the withholding of treatment from children who have treatable illnesses. Much more must be done to halt what remains the subjective practice of withholding medical treatment to critically ill newborns.

It is extremely important that we remember that the vast majority of handicapped newborns go on to lead productive lives. Many grow strong, learn to read, care for themselves, and with some luck, enjoy life, love, and the love of others. As do all children, they bring with them varying amounts of burdens and rewards.²⁰³

Perhaps a uniform law which grants every newborn the unconditional right to life, unfettered by arbitrary medical or legal judgments, is in order.

203. NAZARIO, *supra* note 5, at 83.